Perspective

From the First Visit On: Information Technology and Communication

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If we were to imagine the failure of the promise of information technology (IT), it might have the flavor of a Saturday Night Live segment.

Knock, knock

"Come in." (Mrs. S sits fully clothed on the exam table facing the door)

"Good morning Mrs. S, I'm Dr. H. I am pleased to meet you (shaking her hand). Let me just check you in on the computer and we can review your data." (Dr. H moves past Mrs. S to the computer keyboard and screen on the writing desk, to the right of and behind Mrs. S)

Looking intently at the screen, Dr. H goes on, "Let's see, you were sent by Dr. J because you had a breast biopsy that turned out to be cancer. It looks like it was a small tumor, about 2 centimeters.

And here we are—the hormone receptors appear to be both negative—and it looks like the HER2 receptor is negative as well, which means you have a triple negative tumor…And, oh my, look at that Ki-67!"

Getting up, Dr. H barely makes eye contact and leaving the room says, "Well Mrs. S, we have some work to do. The nurse will be in shortly to give you a gown so we can do an exam and talk about what will be next."

The Promise of IT

In 1991, the Institute of Medicine (IOM) called for conversion of the paper-based delivery system to a computer-based system, meaning an electronic health record (EHR).[1] With little movement from paper in the preceding decade, the call went out again in 2001, calling for conversion to a paperless office using EHRs by 2010. The goals were to improve the safety, quality, and efficiency of health care.[2]

In 2003, the IOM reported on eight functionalities possible with widespread EHR adoption. These were (1) health information and data, (2) results management, (3) order entry and management, (4) clinical decision support (CDS), (5) electronic communication and connectivity, (6) patient support, (7) administrative processes, and (8) reporting and management of populations. In this setting, communication referred to communication among providers and accuracy and availability of data. Communications with patients received little mention.[3]

A systematic review published in 2006 looked at the state of EHR capability and penetrance.[4] The authors found that only a few institutions had enough experience to contribute to the literature. Even so, five domains of activity were identified: (1) delivery of care in adherence to guidelines and protocols, (2) enhanced capacity to perform surveillance and monitoring for disease conditions and care delivery, (3) reductions in rate of medication errors, (4) decreased utilization of care, and (5) mixed effects on time utilization.

A more recent article by Warner and Hochberg[5] lists three major functions of EHRs to improve quality and costs: (1) enabling effective communication, (2) fostering CDS technology, and (3) generating structured data. These authors mention the patient portal as a means of communication. This is no doubt spurred by the changes in health care law in the last 4 years.

The opening vignette reminds us that our primary communication is with patients. The EHR and much of the initial activity were not directed at this process. There are many aspects of communication, from data sources (laboratory tests, imaging, pathology) to providers, among providers and specialists, within the care team (nurses, physicians, pharmacists), and directly with patients. The remainder of this article discusses two arcs of communication in the trajectory of disease that occur directly with patients.

From the First Visit to Survivorship

This arc has a defined end point, the completion of treatment for a potentially curable tumor. This is followed by an ill-defined period of surveillance and survivorship. Three aspects of this arc have a substantial communication component that benefits from IT.

For the initial visit, the patient portal changes everything. In this environment, physician clinic notes, laboratory results, and imaging results can be made available in a secure fashion for patients to access as they desire. Communication is then facilitated by patients' ability to review their records with little lag time. This achieves a transparency that few had previously imagined. A recent report[6] from three large primary care practices (PCPs) noted little downside to open access to physician notes and overwhelming acceptance by patients, with little resistance by physicians. Although oncology records may be perceived as more sensitive than PCP notes, the use of the patient portal will become widespread, and the initial visit will be characterized by the physician and patient reaching an agreement as to how to share clinical information.

For those completing treatment, patient records on a portal can be available to the patient at any time. A treatment summary can be done in the form of an end-of-treatment progress note. Alternately, a standardized form could be automatically

populated with the treatment regimen, adverse effects, complications as they have been compiled during the treatment course, and pre- and post-treatment medications. An information center for patients (and referring physicians) with surveillance schedules and any new relevant data can be accessible.[7] Currently, time expended by professional staff is a disincentive to expanding these programs.[8] IT could help address this problem.

The third component involves maximizing the patient experience through the course of therapy. This involves team care in which physicians, midlevel providers, and nurses have defined roles in communicating with patients to reduce symptom burden, complications, and emergency room and hospital visits. The US Oncology Innovent program,[9] the Oncology Patient Centered Medical Home model,[10,11] and the Cancer Care Ontario symptom assessment program[12] have taken steps in this direction. Each involves systematic data collection and reporting using EHRs.

From the First Inflection Point to End-of-Life Care

For cancer care, an inflection point signifies a change in direction. This may occur at the diagnosis of an incurable cancer, a recurrence after adjuvant or potentially curative therapy, progression after first- or later line therapy, or ceasing aggressive therapy altogether. We have found that communication is key to the patient's quality of life, the well-being of family members, hospice enrollment, and costs.[13-17] The challenge is to make these conversations happen. There are (at least) three strategies that can be pursued to improve these outcomes.

The first is to carry through the promise of open communication as typified by the patient portal. The communication is defined as transparent from the beginning, and inflection points are visible for all to see.

A second strategy is to use CDSs to emphasize these inflection points. This is a prominent aspect of pathways programs. Within this technology, late-line chemotherapy regimens for which there is no evidence of benefit becomes difficult in that the regimens are not easily accessible and may require peer review for approval. Two studies show reductions in late-line chemotherapy and costs associated with this process, with no affect on survival.[18,19]

Third, team-based care can improve the amount and content of communication so that multiple providers can collect data and lead patients to full discussions regarding treatment choices. The goal is to create multiple touch points by different practitioners.[20] This can begin with the first chemotherapy teaching session. We can do systematic symptom assessment. We can have ready access to palliative care. We can add routine questions about advance directives, and we can do a systematic query on values. All of these can be a bridge to high-quality end-of-life care.

Do We Have What We Need in IT?

The short answer is, for most of us, no. Portals are not widespread, EHRs are not designed for routine symptom assessment and follow-through, and it is not easy to get a date of death or hospice admission into the record as a discrete data entry. Most clinicians do not have CDSs with identification of inflection points. Survivorship plans are time consuming and inconsistent.[21] However, we can see examples that work and emerging technology that will help.

Closing Notes

In regards to the original vignette, there is an alternative version:
Knock, knock
"Come in." (Mrs. S Is in street clothes sitting next to the writing desk)
"Hello Mrs S, I am Dr H (shaking hands). I suspect you are not sure you want to be here, but it is my pleasure to meet you. It will just take a second while I sign you in (faces the computer, then turns back to face Mrs. S).
"I have reviewed your records and have some idea of your situation. But before we talk about that, please tell me your story and what you think of all that has happened that brings us to this point."[22]

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